

ISSUE #58 WINTER 2020

# AFFINITY

THE MAGAZINE FROM FERTILITY NETWORK UK



# The Fertility Show

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Hello and welcome to the Winter edition of Affinity, Fertility Network's magazine.

This issue coincides with the charity's annual National Fertility Week, this year 2nd November – 5th November. The aims of the week are threefold: it's about changing perceptions and raising awareness of fertility issues; it's also about providing vital support and finally it's about raising much needed funds to continue the charity's work.

#YouAreNotAlone is our core message. Here's what we did during Fertility Week:

Monday 2nd November #FertilityInequalities

To kick-start this important week, we spotlighted inequalities to fair access to fertility treatment for all. We want to see fair and equitable access to NHS fertility treatment regardless of where you live, your race or your sexuality. We highlighted the unacceptable rationing of treatment throughout the UK, the difference in provision between each of the four nations and the postcode lottery in England. We also raised awareness of inequalities in access based on ethnicity and sexuality, of the differences in outcomes for some ethnic groups, and called for fairness for everyone who needs treatment.

Tuesday 3rd November #MentalHealthMatters

Infertility is not only about physical health, but can take a toll on mental health too. The impact of COVID-19 with clinic closures and reduced capacity on reopening has increased distress for many patients, making our #MentalHealthMatters day more important than ever. We shared testimonials from our community as well as tips from mental health experts about how best to look after yourself. This day was about raising awareness of fertility and mental health and offered solutions to help fertility patients navigate this challenging journey.

Wednesday 4th November #MenMatter

Men are half the fertility equation but their voices are not always heard. Men can find it harder to express their feelings, and during the early stages of the COVID-19 pandemic, men reported feeling forgotten and overlooked. During our #MenMatter day, we spotlighted men's voices with testimonials from our male community and experts in the field. We highlighted the need for more tailored support and advice for men, and publicised some of Fertility Network UK's new initiatives aimed specifically at our male community.

Thursday 5th November #FertilityEducation #FertilityInTheWorkplace

Our Fertility Education day looked at why our society needs to be more informed and educated about fertility. We asked why young people are still not aware of the lifestyle factors that could affect their fertility. We also shared the results from our own Fertility Education project #FutureFertility, which is funded by the Scottish Government, and launched our new project in Wales.

We highlighted the need for more education for all, including healthcare professionals and employers, and raised awareness of the importance of our #FertilityInTheWorkplace initiative.

Although Fertility Week 2020 has finished, the campaign has not: share your stories, experiences, blogs using the hashtag #YouAreNotAlone. Host a Fertility-Tea and help raise funds even virtually. We hope that 2020 will be one of our biggest years ever.

Very best wishes, Gwenda



# CRAIG MCALLISTER MARATHON RUNNER

Myself and my wife Kat tried for four years to become pregnant, however, as Kat suffers from PCOS we knew it could be more difficult to conceive. Eventually, in 2017 we were referred for IVF treatment at Oxford Fertility.



Like so many others, we entered our fertility journey with raised expectations, nerves for what might be, and the hope that we might become the parents we so wanted to be. Sadly, on our first attempt we only managed two embryos and unfortunately this led to a failed cycle.

We gathered our strength and decided to have another attempt. However, unlike our first time our expectations were raised when we were told that Kat had 25 follicles. Great, we thought – we may get more quality embryos and an increased chance of success. However, again our hopes were dashed as Kat was suffering from ovarian hyperstimulation syndrome (OHSS).

The consultant explained that the risks to Kat were too great to go ahead with a transfer and Kat needed to recover. Although downhearted, we were consoled in the fact we had 11 embryos all suitable for freezing and we could have a frozen cycle when Kat recovered.

The next year, in April 2018, we once again attended the clinic and, after what seemed like the longest two-week wait, we were over the moon to find out that we were expecting. We were so excited that finally Kat was pregnant and at long last we would become parents. But I cannot put into words the grief we felt when we were told that our precious pregnancy was ectopic. This pregnancy was not to be, and we were absolutely devastated; one minute so hopeful and the next so desolate.

After taking the time to come to terms with the loss, we agreed to have another attempt at a frozen cycle.

We returned to the clinic in Oxford and we had two embryos replaced. As with the last attempt, that two-week wait seemed to last forever! We were so happy to get a positive result however this time we were much

more anxious and scared to get excited.

In September 2018 we had an early scan and were overjoyed to discover we were expecting twins. We were in complete disbelief that finally, after such a difficult and traumatic journey, we could now look forward. Our beautiful daughters Mikeala and Lille arrived on April 7th 2019 and our life has been transformed. Although a difficult journey, full of worry with so many competing emotions we are so thankful for the support we received.

Fertility Network UK are an amazing charity, and with their support I have been lucky enough to secure a place in the London Marathon in 2021. This will enable me to raise awareness of infertility and funds to support the work the charity does to help more people on their fertility journey. I hope you will follow and support me on this too.



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# A SIMPLE INTERVENTION TO KNOW ABOUT

BY NEIL JOHNSON, FROM OUR PARTNERS GUERBET

Women experiencing infertility problems may feel under pressure to start IVF (in vitro fertilisation) treatment immediately.

But there is a quick, minimally invasive intervention they could explore first, potentially increasing their chance of becoming pregnant without the need for IVF. The procedure involves using iodised poppy seed oil and appears to have a positive immuno-biological impact on fertility, possibly by flushing fertility-hindering debris from the fallopian tubes.

However, many patients are unaware this treatment exists — and that's wrong, says Professor Neil Johnson, a fertility specialist based in Auckland, New Zealand, and President of the World Endometriosis Society.

"IVF is involved, expensive and carries the possibility of complications," he notes. "This intervention, however, is low-invasive, cost-effective, carries a very low chance of complications and is very effective."

## What to expect during the procedure?

The iodised poppy seed oil can be administered in a hysterosalpingogram (HSG). "The patient lies on an X-ray bed," Professor Johnson explains. "A speculum is then inserted into the vagina and tubing

is sent through the canal of the cervix. The solution is then gently instilled into the uterus, through the fallopian tubes and bathes the pelvic cavity.

"Very occasionally, there may be some discomfort, but it is not usually painful, and the vast majority of patients tolerate it extremely well. Appointments take around half an hour, but the main part of the procedure usually takes just 10 minutes."

## Particular success for women with endometriosis

An HSG was once a purely diagnostic intervention, where dye is injected into the cervical canal in order to investigate the shape of the womb and fallopian tubes.

However, between 1999 and 2004, Professor Johnson and his team recognised its remarkable therapeutic effects when iodised poppy seed oil doubled fertility within a trial group with unexplained infertility.

The procedure was particularly beneficial for women with a history of endometriosis, an inflammatory disease where tissue that normally lines the inside of the uterus is also found outside of the uterus.

"Endometriosis is a benign condition that can cause abdominal pain, pelvic pain and infertility," he says. "In New Zealand, we've discovered that this procedure has increased the fertility of women with endometriosis, which can have a substantial negative fertility

impact even when the disease itself is not extensive. Indeed, we found that those with a history of endometriosis in our trial group experienced around a four-fold improvement in fertility. We thought it was amazing and have been offering it as a routine treatment for infertility since 2004."

## Patients who are unsuitable for treatment

Nevertheless, there are women who are unsuitable for the intervention. "For example, if a patient's fallopian tubes are blocked or damaged, then the treatment is not going to work, and they should proceed to IVF," says Professor Johnson.

"Other patients who won't find it beneficial include women who don't release an egg — they will need ovulation induction instead — and those whose partners have a low sperm count. However, it is absolutely appropriate for the majority of women who have relatively mild endometriosis-related infertility that hasn't damaged their fallopian tubes. In fact, it's probably their best first-line treatment because it's so effective."

There's now growing interest in the procedure around the world. "That's very exciting," says Professor Johnson. "I think every woman visiting a fertility service should have the opportunity to explore this treatment as a first option, instead of moving straight to IVF."



## Fertility funding: We need a radical new approach from our government

Prof Dr Geeta Nargund, Medical Director, CREATE Fertility

At present, there exists a deep inequality in access to fertility treatment in the UK. A woman's age, egg reserve, whether she is single or in a same-sex relationship and whether herself or her partner have had a child from a previous relationship, all determine whether she is granted IVF treatment. Just this month, it was revealed that women in 24 NHS regions are required to prove that they are in a "stable" relationship before funding is considered.

Further, with an increasing number of Clinical Commissioning Groups (CCGs) deciding to cut fertility treatment funding altogether, thousands of women and couples are being denied the chance to become parents, simply by virtue of where they live. Therefore, although NICE guidelines recommend that women under 40 should be offered at least three cycles of IVF, currently only 12% of regions meet this recommendation.

One way we could look to tackle this is by introducing a National

IVF Tariff to increase the number of cycles that can be funded within the existing budget. Currently, the price paid per IVF cycle differs dramatically between regions, ranging from £2500 to over £6000 for the same treatment. This cost per cycle has a direct impact on the number of couples who can access IVF. By introducing an upper limit for the price any CCG pays for IVF treatment, the NHS could save money whilst giving more couples around the country access to treatment within the existing budget. The NHS already employs this standardised national approach for other medical treatments, so why not IVF?

Currently, our NHS bears the burden of treating women hospitalised following Ovarian Hyperstimulation Syndrome (OHSS) and caring for premature and low birth weight babies born as a result of multiple births from IVF treatment. We could potentially save millions of pounds to the NHS if we reduce these complications by adopting modern treatment protocols and single embryo transfer policies.

The savings could be diverted to funding more IVF cycles.

However, with pressures on NHS budgets only increasing in the wake of COVID-19, it is unfair to place responsibility for IVF funding solely at the NHS' door. I believe that the Treasury, and the departments of Work and Pensions, Health and Social Care, and Women and Equality should also meet the cost of funding IVF treatment for those who need it. This is because crucially, by improving access to fertility treatment, we are also supporting the future social and economic prosperity of the UK. Research shows that, through tax and pension contributions, the economic value of a child born in the UK is over £700,000 over their lifetime, and current birth rates will fail to meet the country's future economic requirements.

It is therefore in our government's interest to tackle the current inequality and invest in IVF funding, not only to give more women and couples the precious chance to start a family, but also to support the long-term economic prosperity of the UK. We need a collective action from our government.





# **Our Journey: Fertility Treatment, Adoption and Family**

**By Anya Sizer**



For many of us, as we grow up there is an expectation of a “natural order” of events. We find a job, meet a partner, settle into a career and then start a family. It is such a presumed course of events, that it makes infertility difficult to navigate.

### **So how do we proceed when familiar terrain disappears?**

As a couple, we experienced firsthand the grief of infertility and the demands of IVF. We were hugely lucky after six years, five rounds of IVF, two miscarriages and huge amounts of investment (on every level) to have our two children - and yet we had also always wanted to explore adoption.

For us, the actual process of being matched with a child was relatively easy. It took far longer than it should have done, three years in total from start to finish, when these days it takes under a year.

However, the process felt positive and hopeful, the absolute antithesis of fertility treatment. There were certainly huge numbers of forms, home visits and hurdles to go through, but there was an end goal in sight. For a couple who had spent so long navigating uncertainty, this was a huge relief.

However, I would now challenge our initial assumptions that it was basically all the same and just another route to parenthood. Adoptive parenting is so much more demanding than that, and as Krish Kandiah CEO of the Home for Good adoption charity so rightly puts it:

“Ultimately adoption is not about family completion, but the flourishing of vulnerable children.”

Our son came to us aged 15 months, a tiny bundle of energy, wonderful but scared and angry about the change in his environment. We faced months of barely any sleep and days when we were all exhausted and overwhelmed. It was a lonely time when we felt we really should be coping well but in reality, each day

felt like just scraping by.

Our son was diagnosed early on with Foetal alcohol syndrome, a lifelong debilitating condition which means he will always require extra support and care. It was a gradual process of coming to terms with this, and has involved battles on many fronts, which it still does and always will.

Parenting a child with additional needs has challenged us far beyond what we thought was possible. At times it has stretched us to breaking point. Adoptive parenting is certainly equal in terms of value but not in terms of demand.

However, after some time we discovered a new normal. A new way of being a family. We found the support that we all needed in terms of educational care, medication and a new tribe of people who would carry us through. We have learned to persevere, to lower expectations and to love unconditionally in a way we had previously never had to.

Adoption has completed our family and we have a lively, funny affectionate bundle of craziness to call our son, a brother who we love equally to our birth children. We would not change it for the world, even though the process has been more costly than we could ever have imagined when we started.

### **What, then, have we learned in all this?**

The first thing I would argue is that adoption is an incredible option, but not one for everyone, and certainly not one that should be continually the domain of the infertility community. To do so demeans both the child and prospective parent.

The average age of a child up for adoption in the UK is just under four years old. They will almost certainly have a history of neglect and abuse, and may have special needs. The realities of parenting such a child mean that “normal” parenting is

often not the most helpful route. A new therapeutic model of parenting will be almost certainly needed.

As such, we really do need to be realistic and sensible about who investigates adoptive parenting, and we certainly need to challenge the concept of “just” adopting. There is no just in adoption.

There is some fantastic training about this and some useful books, but the reality is that you can only prepare so far without meeting your child. Looking into the realities of adoption, working out how you will best support yourself going forward and putting structure in place is essential.

The second key learning point is the fundamental need for support when adopting a child. Another phrase I used to happily throw out before we met our son was that it “takes a village to raise a child”.

Since becoming an adoptive parent, I know now this is not just true but vital in making such a family work and holding onto hope during the almost inevitable turbulence. As with infertility, we have sadly found that some people will just not understand or be able to empathise with your experience.

However, there will be others who do, who stand in the gap for you when life just seems too difficult to navigate. We will always be grateful that we found our tribe and for the amazing support we have found along the way.

Ultimately, adoption can be a wonderful option for becoming parents but perhaps even more importantly can be an incredible option for the child. It is not for everyone, nor is it a second-best prize.

Finally, then to return to my original question: how do we proceed when familiar terrain disappears?

With fertility treatment and adoption, the answer is that we build a new terrain. Slowly, and at times with uncertainty, but we build and we make something new. We make our own definition of family.





That means that men can improve their next batch of sperm if they find their sperm aren't well. This puts men back in control.

With the right advice, men can protect and improve their sperm health. The good news is that lifestyle changes can bring about rapid improvements. Here are some easy ways to improve your sperm health:

1. Stop smoking: Preparing for parenthood can be a great opportunity to quit smoking and improve the health of you and your family. Giving up cigarettes can increase your likelihood of becoming a parent, so why not make the change now?
2. Reduce your stress levels: Not only can stress put you off sex, it also produces free radicals, which can damage sperm DNA. Taking some of the stress out of your life can go a long way to improving your sperm quality.
3. Get healthy: Being at a healthy weight gives you the best chance of producing sperm of good quality and quantity. Regular exercise and healthy eating are essential to lose weight and maintain a balanced lifestyle.
4. Cool off: Your testes are where they are for a reason – sperm production works best at a lower temperature than inside your body. Try to avoid activities that increase your testicular heat, such as wearing lycra shorts or tight underwear, spending all day sitting at a desk or even doing lots of cycling.
5. Avoid drugs: Cannabis damages sperm in many ways including slowing them down and changing the way they act, making it harder for them to find the egg and to penetrate it when they do. Regular cannabis use over a few years can permanently reduce a man's ability to make sperm. Even if you don't take drugs, some protein shakes and health supplements contain steroids which can also damage sperm.
6. Don't use supplements unless you have been tested and found to have high levels of ROS. We are inclined to think 'over the counter' vitamins and antioxidants can't do us any harm. That's not true. Too many vitamins can cause serious damage to our sperm. Save your money instead.

Have you been told that fertility experts can't find anything wrong with you?

You are not alone. Believe it or not, more than a quarter of couples having fertility investigations are told that neither of them have any detectable problems. This is a disappointing

conversation for clinics and couples alike. When men have a normal semen analysis, this also means that they won't be investigated any further. If there is no diagnosis; there can be no personalised solution.

This can lead to expensive, invasive, prolonged and often unsuccessful cycles of treatment. Further tests for couples with 'unexplained infertility' can be really useful. For example, research has shown that 75% of men with 'unexplained' infertility have high DNA damage in their sperm. If men find out they have high DNA damage, they can take steps to improve it in the next batch of sperm they make.

The importance of understanding men's role in miscarriage

We don't usually think of miscarriage as a form of infertility, because the couple did get pregnant. Yet in broader terms, we might think of all couples that can't have a baby as having fertility problems.

When we think of pregnancy loss, we usually think of the mum. We often forget how important the dad is in creating a healthy baby as well. As discussed earlier, men with high levels of sperm DNA damage take longer to get their partner pregnant and have double the risk of miscarriage.

In a new study just published by Professor Sheena Lewis, Dr Hassan Shehata and Dr Stephen Gordon, sperm DNA damage in men whose partners have miscarried was compared with that of men who had babies recently. The Examen test was used to assess the average level of sperm DNA damage, the proportion of sperm with low DNA damage and the proportion with high DNA damage, to determine whether these are reliable indicators in the diagnosis of miscarriage.

Male partners of women who had miscarried were all found to have much higher sperm DNA damage than fertile men, and the Examen tests were highly predictive of both sporadic and recurrent miscarriage. This shows that sperm DNA tests are a powerful tool for understanding and predicting pregnancy loss, and lead to new fertility pathways for couples struggling with miscarriage. Men who have experienced miscarriage should visit a urologist, a specialist doctor trained and focused on male reproductive problems.

The latest treatments for male fertility

For men who have low sperm counts or high sperm DNA damage, ICSI is the best treatment because only one sperm is needed, and the

egg has a better chance of repairing the sperm DNA breaks in ICSI than in IVF. For those couples who have had several failed ICSI cycles, donor sperm used to be the only route left for them. New solutions are now being explored.

Scientists have found that when men have high DNA damage in their ejaculated sperm, it is possible to take sperm from the testis and use them in ICSI instead. The success rates with this treatment are very good and it is becoming more popular. It is done as an out-patient procedure, with plenty of anaesthesia so you won't feel a thing!

The importance of having healthy sperm

Poor semen quality is not just linked to a man's fertility. It is also linked to cardiovascular risk, later onset cancers, and shortened life expectancy. So, it's worth keeping an eye on sperm health as a check of overall health.

For your children's health

Sperm quality can also impact your children's health. So, if you find it hard making lifestyle changes for yourself, do it for your kids.

We hope that all of this new information will help more men become dads.

Living the 'new' normal

As of September 2020, COVID-19 restrictions have eased enough to let clinics open again. However, post-COVID we don't have time for several ART cycles. We need a better diagnosis and a better understanding of how to optimise our sperm for the next treatment cycle to give ourselves the best chance that that cycle alone will work.

If you're feeling overwhelmed by delays and isolated as you try to get through your fertility crisis during the pandemic, then know that you're not alone. Many couples are experiencing the same feelings as you. We know you are worried about when you can get treatment and if COVID-19 will affect your pregnancy. Fertility Network UK is here to support you.

[fertilitynetworkuk.org/trying-to-conceive/fertility-treatment/male-issues/](https://fertilitynetworkuk.org/trying-to-conceive/fertility-treatment/male-issues/)



## Graham's Story

By Michèle Wright

A FEW WEEKS AGO, I WAS LUCKY ENOUGH TO MEET GRAHAM HUNTER. HE WAS ONE OF THE FIRST PATIENTS THROUGH THE DOORS AT BOURN HALL, THE CAMBRIDGESHIRE FERTILITY CLINIC OPENED IN 1980 BY ROBERT EDWARDS (LATER SIR) AND PATRICK STEPTOE, BOTH NOW SADLY DECEASED.

This is Graham's fascinating story; the treatment options for infertility were very different in the 1970s, but the emotional impact was just as devastating as it is now and the moral dilemmas associated with treatment remain.

Graham and his wife Lesley married in 1972, when they were both 21. Later that year Lesley was very ill, resulting in her losing a fallopian tube and being told she would never have children. In 1975, they heard that Robert Winston had pioneered a technique to unblock tubes and as they were desperate to have a family, Lesley underwent surgery. Sadly, this was not successful and had a massive impact on her mental health.

In 1978 the first test tube baby, Louise Brown, was born in Oldham. Graham and Lesley wondered if they might now have a chance of a family and so, in 1980, they wrote to Bourn Hall asking for help. They were accepted for treatment and began the first phase - taking Lesley's temperature every morning for three months, to detect a temperature increase that would indicate ovulation.

The only treatment available at the time, the one that Edwards and Steptoe had been researching, involved fertilising a single egg outside of the body. Lesley and Graham stayed at Bourn Hall for the three days before Lesley ovulated. And on the morning of her temperature increase, Lesley was rushed into theatre for a single egg recovery by laparoscopy. Timing was critical as the egg had to be retrieved as soon as it was released from the ovary but before the fimbrial end of the fallopian tube could catch hold of it and propel it towards the uterus.

As if this were not complicated enough, whilst the laparoscopy was taking place, Graham had to produce a semen sample whilst a nurse waited outside an upstairs bathroom!

Once the egg was collected, it was suspended in a special fluid culture medium and the prepared sperm sample was simply added to it in a petri dish. It was then incubated for several hours and viewed frequently under a stereo microscope to see if it had fertilised. Incubation continued for two or three days until it reached blastocyst stage, and then it was reintroduced to the uterus via a catheter. It was a very exacting task as it had to be introduced into the right area of the uterus at the right time and although ultrasound existed, it was very basic.

The treatment available in Lesley and Graham's time was in stark contrast to the standard procedure now, where an artificial menopause is induced, followed by super-ovulation via hormone injections and the eggs collected via transvaginal ultrasound. The men's rooms also tend to be slightly more luxurious and 'well equipped'!

Unfortunately, Graham and Lesley lost their much-wanted baby at six weeks. This had a further impact on Lesley's mental health and ultimately the marriage ended. In an ironic twist of fate, Graham went on to sell IVF equipment all over the world. He started his own company, Hunter Scientific, which specialised in microtools for IVF and had a multi-million-pound turnover by the time he retired in 2012.

By 2010 it had become possible to assess the quality of an embryo through timelapse photography, enabling a thorough analysis of the cell division that has taken place. The fertilised egg is monitored for three days to check that division has taken place correctly and without granulation. During this period, it is now also possible to diagnose genetic conditions via pre-implantation genetic diagnosis (PGD), to look for suspected diseases such as cystic fibrosis. To do this, a cell is surgically removed from the embryo at the 4 or 8 cell stage and a chromosome map is produced to look for that specific disease. PGD only became possible after Intracytoplasmic Sperm Injection (ICSI) was perfected, and initially only a few diseases could be screened for as the genome had to be found which coded for them.

Techniques and knowledge have advanced a great deal over the last 45 years, but complex moral dilemmas remain surrounding those embryos that are not 'good enough' or surplus to requirements. Some unwanted embryos are donated for implantation and some for stem cell research. Further complications can arise as there are limits as to how long frozen eggs, embryos and sperm can be stored. However, the most emotive (and legally challenging) problems arise when a couple separate, and one party, for example, wishes to use their frozen material with a new partner.



# It Takes a Village

Written by Vanessa Haye

Contributions by Afryea Henry-Fontaine and Noni Martins

"Have you been to see the doctor yet?" This question will go down in my history books as one of the most forward questions I'd ever received from a family member during our journey of trying to conceive our first child, three and a half years into failed fertility treatments.

Whilst it was extremely out of the blue, at least it wasn't as bad as the all familiar question: "When are you going to have children?" This type of question, which I could never seem to avoid answering in family socials and friendly catch-ups, seemed much worse because it summed up the epitome of why many couples in some communities will struggle with infertility in silence and shame. It is the presumptuous thinking that a couple can successfully start a family with no issues, while setting a timeline against that, which is typical of pronatalist attitudes in some communities, and particularly Black communities.

I was victim to these unwelcome remarks, as gaining a degree, securing a 'good' job afterwards, getting married and finally starting a family was the idea of 'success'. These social and cultural norms are what caused me to feel alienated and alone when I had achieved all but one milestone by the age of 27. I felt that I had failed my husband, my parents and even my siblings. Even though I got through my 'secret battle' by joining online forums and chat groups, there were some issues discussed that I never felt could be understood in great detail, due to very specific beliefs and behaviours that were held in my culture, and so it was a very isolating and lonely experience.

Five years later with our two-year-old son, I often reflect back on those difficult times and when speaking with other women and couples from my Black community who were experiencing the same issues I faced, I felt a strong urge to hold a safe space for other Black women who require the support network I didn't have. So Femelanin was created, a community-based organisation that provides a safe and uplifting space for women to share their intersectional experiences.

Here are a few inspiring and encouraging stories to read from two women, who like me found their own ways to cope through infertility between our community's 'walls of silence'.

"My name is Afryea and I had always desired to be a mum. From a young age I had already naively predicted how many children I would have. My husband and I decided we wanted to start a family as soon as possible following our wedding, however we struggled to conceive due to my irregular and then absent cycles. After being continually turned away by the NHS with no real direction, we sought a second opinion and discovered I had significantly elevated Prolactin levels, which were causing my body to think my body was already pregnant. Following multiple scans, invasive tests, holistic womb support - we found a medication that worked and reinstated my cycles. We were blessed with the birth of our beloved daughter who was born in March 2019.

The hardest part of my journey was constantly being in the unknown, and for such a long time having no diagnosis or understanding of what was blocking my fertility. I had the fear of not being able to fulfil my dream of motherhood. So many people around me had been able to fulfil that dream for themselves and were understandably looking to us for when we would join what felt like the exclusive parenthood group. As we chose to keep our challenge quite private, aside from family and a few close friends, it heightened the feeling of loneliness and anxiety all the time. To remain optimistic and positive, I turned inward and tried to cultivate my inner peace. Meditation and seeking holistic ways to assist my body in the process grounded me and helped to maintain a positive outlook, even when things were most challenging. I wish I knew more about the varying ways women can be affected by infertility or challenges with conceiving. It's not one size fits all." - Afryea Henry-Fontaine

"For a long time, I felt shame, not because I was being made to feel ashamed externally, but because I was ashamed within myself. My experience forced me to ask myself where these feelings come from, and when I wrote my first blogpost and got responses like "this is a taboo topic" and "I'm sure your husband still loves you", it hit me. All those years growing up in Zimbabwe, the indoctrination, especially as a black girl: the whole idea around servitude to the man I marry and his legacy, what we are taught about womanhood and the strong focus on motherhood as huge part of that.

For Southern African women whose spouses pay 'lobola' (a bride price) for them, infertility comes with yet another dimension where a woman can feel that she has to prove or show her worth by giving the man a child. My husband paid lobola for me and although I am evolved and his family is equally evolved and incredibly supportive about our situation, internally in the back of my mind I have thought about it. Growing up, I used to hear stories of women being sent back to their families because they couldn't fall pregnant, with the man's family demanding their money back.

These might have been just stories but even then, why such stories? Just imagine the lasting impact - I am 31 now. My feelings of shame, and the silence I maintained were rooted deep in my upbringing, even when my current lifestyle is that of a liberal surrounded by other liberals. Our ethnicity and cultures play a big part in who we become and what we subconsciously believe and hold onto.

My infertility journey has taught me to challenge and unlearn all these belief systems. Finding other black women in this struggle affirms my new perspective." - Noni Martins







# The Future of Fertility Travel

A recent online survey, believed to be one of the largest ever to be undertaken on fertility tourism suggests there remains a substantial number of people who are prepared to travel, and travel far, for the right treatment.

The recent 2020 Fertility Travel Survey was undertaken by the International Fertility Company, in partnership with Fertility Network UK and other fertility organisations. The work was conducted against the backdrop of border closures and COVID-19 travel restrictions.

Co-authors Andrew Coutts, Jakub Dejewski and Alex Wiecki paint an optimistic view of future patient travel. 77% of survey participants (over 500) had not travelled for treatment previously, but 97% of all participants said they were actively considering it for the future.

Those participating in the survey were from Europe, Canada, Australia, India, the US and across Asia. The most popular treatments sought after were donor egg treatment and IVF with own eggs, while 10% of participants were seeking surrogacy options. Spain remains the most popular fertility destination, although countries like Greece, Cyprus and the Czech Republic are emerging as favourites for younger patients driven by cheaper prices. However, price is no longer the absolute driver for travel for all age groups.

The UK and US were the preferred locations for 5% of participants from all age groups, but significantly, this rose to over 12% of those aged over 35. Interestingly respondents were prepared to not only travel, but travel long distances as Andrew Coutts explains: "Prior to travel restrictions being imposed, we were seeing individuals and couples travelling considerable distances for treatment at specific clinics or with specific doctors. We saw American patients travelling to the UK, South Africa and India; Australian patients travelling to Spain; and Chinese patients travelling into Eastern Europe. Judging by responses from the survey we don't see any reason for this to stop once we can all travel freely again."

Participants demonstrated a realistic approach to the cost of treatments, with 69% saying they were expecting and prepared to pay over £5,000 for egg

donation treatment and 55% said that were expecting own egg treatment to cost between £2,500 and £5,000. A range of funding sources were identified to pay for treatment which included loans from family, friends and banks, savings, credit card payments, re-mortgaging property and crowdfunding proposals.

Potential travellers were attracted to treatment providers for a variety of reasons. Many cited the availability of donors and treatments; smaller waiting lists, success rates, clinic experience and reputation and positive feedback from former patients. Although donor anonymity was a reason for some to travel it was not a key driver. Participants were also asked what would negatively affect their decision to travel and these responses varied dramatically by age.

The 18-24 year old group overwhelmingly cited perceived language difficulties (48%) and being away from family and friends (27%) as potential barriers to accessing treatment abroad. Anxiety about communication dropped to 6% in the over-45 group and 10% in the 35-44 group, who both identified the level of regulation being the crucial determinant of travel choice. Interestingly only 4% of respondents said they would be put off travelling by hearing individual horror stories online.

It is apparent from participants' feedback that there is a significant interest in travel, yet 86% of those questioned said that although there was a lot of information on fertility travel available, it was not enough. Quite understandably against the backdrop of the COVID-19 pandemic, online interaction was preferred at the time of the survey with participants highlighting the desire for more digital access to clinics and staff, consultations and telemedicine orientated communication.

There was a call for more pre-travel testing to become available in order to reduce the amount of time spent away from home during treatment and there was overwhelming support for treatment providers to incorporate wellness activities into core treatment packages.

Andrew Coutts sums up the work:

"There is a lot of first-hand information in this survey which can help those thinking about travel. We hope that it will also act as a useful resource for treatment providers, enabling them to consider support services and treatments that are responsive to patient needs."

The full report from the survey is available here: [Internationalfertilitycompany.com/news-blogs/#survey](https://Internationalfertilitycompany.com/news-blogs/#survey)







# Fertility Yoga

Fertility Network UK responded to the COVID-19 pandemic when clinics closed, and treatment was cancelled, by reaching out to patients to support them emotionally. We were overwhelmed by the response to our Fertility Yoga classes and the feedback has been so positive from patients that we are continuing to hold weekly webinar classes.

Our teacher Annie Perry, now known by so many fertility patients across the UK, has taken some time out of her busy schedule to tell us more about the benefits of Fertility Yoga.

Yoga has an incredibly positive effect on emotional and mental health, something that is imperative to nourish when going through fertility treatments and struggles which are physically, emotionally and financially demanding.

One of the most widely recognised benefits of yoga is its role in stress reduction. Numerous studies have shown it to be effective in reducing stress in a broad range of populations. There is no question that ongoing fertility challenges are stress-producing. A study by Dr Alice Domar at the Harvard Medical School documented that the anxiety and depression levels of women facing fertility challenges was on a par with the levels of people who had been diagnosed with terminal diseases (Domar, 2002).

In turn, stress can negatively impact our ability to become pregnant when the adrenal glands pump stress hormones such as adrenaline into the bloodstream and thus rob the uterus and ovaries of the rich blood flow and oxygen they require to function optimally. Yoga on the other hand can elicit the 'relaxation response', a term coined by cardiologist Dr Herbert Benson in the late 1960s.

Yoga and meditation are particularly effective in eliciting the relaxation response. They activate the parasympathetic nervous system, allowing the body to reverse the physiological effects of the fight-or-flight response, and instead activating the relaxation response. Interestingly, the hypothalamus gland, which mediates the relaxation response also regulates all aspects of reproduction. (Domar, 2002)

The aim of Fertility Yoga classes is to elicit the relaxation response in patients going through fertility struggles, while also tailoring the physical yoga postures according to the menstrual cycle and/or treatment stage. Breathing techniques (pranayama) and meditations are also used to help to balance complex emotions, aid sleep and rest, help to develop self-compassion, and finally to help the patient feel more empowered and in control.

Annie Perry  
YogaBellies Teacher of the Year 2019!  
BA (Hons), MSc, Certified YogaBellies Teacher (300 hours), Birth ROCKS Mentor, Fertility Yoga Teacher, Pre- & Post-Natal Massage Therapist

# Peanut's TTC Community

By Sophie Sulehria



I thought that depression and anxiety wouldn't "happen" to me. I have a great job, wonderful family and friends, a loving husband and a lovely little house. We want for very little, what would I have to be depressed about?

We'd been trying for a baby for only a few months, but I knew internally that something was very, very wrong. I had been bleeding between periods and I was in a lot of pain, a lot of the time. For years doctors had diagnosed me with a string of incorrect illnesses, from IBS to anxiety to potential Crohn's Disease - no one really considered it could be gynaecological. The truth was harsh as I was in fact suffering with severe endometriosis, undetected in my youth despite copious trips to the doctors and the long list of symptoms.

I went on to have two surgical procedures, which led to a worse conclusion – a damaged egg supply. My husband Jonny and I were told it would be unlikely for us to conceive children naturally. We were to join the thousands of other couples in a secret club that no one wanted membership for. £50,000 worth of IVF treatment later and things looked bad for us, round after round of disappointment, the prospect of becoming pregnant seeming more and more unlikely.

I'd never experienced depression or anxiety before. Sure, I'd been low, but this was entirely different. Now I was finding everyday life hard to navigate, and I could think about nothing other than being pregnant.

Worse still, it felt like everyone else around me was able to achieve this goal that I couldn't seem to manage. I became hyper sensitive to pregnancy, pregnancy announcements and other people's children. Every time I turned on the TV, baby images haunted me and pregnancy test ads popped up. Every person I met in the street seemed to be either pregnant or holding their gorgeous newborn. It was torture,

and I felt like the world was out to get me. I would start the day fine, be out for a walk in the park, only to look up and notice a group of women enjoying their babies and exchanging experiences. A group I believed I would never be a part of. My heart would start racing and my mind would fall down a rabbit hole of lost dreams. Next thing, I would be in floods of tears and heading home, unable to move from the sofa or bed for the rest of the day. It was traumatic, heart-breaking and debilitating. For a time, I stopped leaving the house unless it was absolutely necessary. I stopped shopping in case I accidentally went the wrong way and found myself down a baby aisle. I stopped walking in case I bumped into a bump. I stopped living for anything other than having a baby.

Special occasions too become a nightmare. Mother's Day stopped being about my own mum and instead she would spend her day consoling me. Christmas will only ever remind me of children; it never feels like an adult occasion. And don't get me started on baby showers! My mental health was deteriorating and I had become withdrawn and depressed. Worse still, I didn't know anyone else in the same boat as me; I had no one in my life who truly understood what I was going through. Yes, I had friends who I could talk to, but I needed to find people who got this extremely complex situation. I wanted to ask questions and find out how other people coped. I craved hope, and support, and advice. I needed a TTC community.

At around this same time, my best friend Michelle Kennedy anxiously told me about her new business idea called 'Peanut'. She wanted to build a social networking app for mums to meet, chat and learn from each other.

"I feel hideous that while you are going through all this, I am starting an app for mums – it's the worst timing for you." I didn't mind. She had her son Finlay at a time when I couldn't support her in the same way I would have liked, and she herself had felt isolated. She needed support as much as I did. Her app, Peanut,

was going to connect women like herself, in need of this support and friendship. She was creating a community for mums. And perhaps she could help women like me too.

"You do this," I said to Michelle. "You make this app, and you make a success of it. And once you have, you need to create another app, an app for women trying to conceive, for women like me. Because while motherhood can be lonely, struggling to become a mum in the first place can be even more lonely."

In 2019, four years after that conversation, Michelle asked me to come into her office.

"I want you to look at something," she said. As she talked me through the yellow slides on her laptop I sat and cried.

Michelle had created 'Peanut TTC' with the most incredible thought and care. She had produced a platform for women struggling to conceive via her Peanut App. At the click of a button, women TTC would be able to access support immediately from other women who understood exactly what they were going through. This meant we'd have our own community on Mother's Day, or Christmas, or on a random Sunday afternoon while the world was with their children, whenever we'd need them. Those in this safe space could lean on each other, through treatment, and miscarriage and negative pregnancy tests, through it all there would be advice and love and support. And it's incredible.

Now, almost two million mothers, expectant mothers and women trying to conceive have joined the app, to connect and share their experiences in a safe space. They all now have community. My only wish is that it had been around sooner.

You can download the Peanut App here: [www.peanut-app.io](http://www.peanut-app.io)





# GUT MICROBIOME

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## *Can gut microbiome improve fertility in PCOS women?*

PCOS is one of the most common causes of infertility around the world, affecting approximately 20% of women who of a child-bearing age. Many believe the real number could be significantly higher.

A key feature of PCOS is insulin resistance - this disorder is present in around 70% of sufferers.

High insulin levels encourage the ovaries to over-produce testosterone, which then contributes towards the various symptoms of PCOS: irregular periods, and irregular or absent ovulation, which lead to reduced fertility as well as acne and unwanted hair growth.

Recently we have begun to understand that it is not simply the food we eat but also our gut bacteria that can affect our blood glucose and insulin levels.

In fact, the nature of our gut bacteria is a better indicator of these factors after a meal than the carb content of that meal.

The gut microbiome encompasses the millions of resident microorganisms inside the human intestinal tract that contribute to multiple health-related functions, including the absorption of key nutrients.

Studies have closely linked the gut microbiome with a variety of diseases.

Endocrine functions (the way the body produces hormones) and metabolic functions (chemical reactions in the body's cells) can be affected by gut flora (normal bacteria).

The expression "leaky gut" is getting a lot of attention in the medical field. Leaky gut, also known as increased intestinal permeability, occurs inside our digestive system. We have an extensive intestinal lining covering more than 4,000 square feet of surface area. When working properly, it forms a tight barrier that controls what gets absorbed into the bloodstream.

An unhealthy gut lining and / or changes in the microbiome could lead to problems within the digestive tract and beyond.

There is a great deal of research currently showing that modifications in the intestinal bacteria and inflammation may play a role in the development of several common chronic diseases, including PCOS.

Studies show women with PCOS have a different balance of gut bacteria that can reduce the absorption of nutrients, including myo-inositol.

Improved absorption of myo-inositol can help better control insulin levels and hormone balance.

Chronic inflammation is a key contributor to the development of PCOS. A dietary trigger such as glucose can incite an inflammatory response in the body. If you have high inflammation markers, it is likely that you will have higher testosterone levels and vice-versa, thus impacting your fertility.

### Improving the gut microbiota in PCOS

Research suggests that improving levels of gut flora will support an improvement in PCOS as effectively as the drug metformin.

Probiotic treatment could be an effective way in treating women with PCOS. In addition to this there are several ways these women can improve their gut health:

- Eat plenty of fibre
- Eat a variety of vegetables
- Avoid high protein diets such as a paleo diet
- Eat olive oil – 1tbsp daily
- Eat fermented foods/dairy products – e.g. sauerkraut
- Avoid tap water – chlorine kills off gut bacteria

Another key consideration is supplementation:

Women with PCOS who are not ovulating may consider myo-inositol, however 40% of women with PCOS cannot absorb myo-inositol effectively.

Choosing a myo-inositol product with alpha-lactalbumin (a whey milk protein) helps reduce the inflammation associated with PCOS and stimulates the intestinal flora growth, thus increasing intestinal nutrient absorption of myo-inositol and facilitating the release of melatonin, which has been shown to improve egg quality.

For more information about fertility, PCOS and balanced supplements that will support men, women and your future family, visit: [www.fertilityfamily.co.uk](http://www.fertilityfamily.co.uk).

## Inofolic® Alpha

The PCOS supplement for women for life

**95% of PCOS women experienced restored ovulation when taking Inofolic Alpha® for 3 months.<sup>1</sup>**

“ As well as myo-inositol and folic acid, Inofolic Alpha contains alpha-lactalbumin which can improve the intestinal absorption of myo-inositol, reducing chronic inflammation and decreasing blood glucose levels. ”

*Dr Gill Lockwood,  
Medical Director and Fertility Specialist*



1. Montanino et al. 2018

**Fertility Family** is dedicated to providing information and support to help people wanting to build their own family...

[fertilityfamily.co.uk](http://fertilityfamily.co.uk)

Brought to you by **Pharmasure**. A UK pharmaceutical company specialising in fertility support for over 20 years. Our range of products are recommended by fertility specialists across the country.



# News from Wales

## #YouAreNotAlone

When COVID-19 was declared a global pandemic, we instantly moved our fertility groups online. Since then, we have hosted many guest speakers and clinical experts who have delivered informative and varied talks, and over the summer, we continued to introduce more groups across Wales.

Both Bangor and Carmarthenshire launched in July, looking at investigations, referral pathways, COVID-19 implications, and re-starting treatment. In August, our All Wales Information Group kicked off with an Andrologist focusing on male factor and sperm cryopreservation; and in September, Men in Wales launched with racing driver Toby Trice, who spoke about his own fertility journey and how he uses motorsports as a vehicle to break the ice and start conversations amongst men.

Women reported feeling “incredibly supported” by us during their fertility journey, but “lost” and “isolated” after they became pregnant. Anxiety in pregnancy is very common, but it is especially acute for those who have struggled with fertility issues. With this in mind, we launched our Pregnancy After Fertility Treatment & Loss group with a specialist infertility and miscarriage counsellor.

We would like to thank all the professionals for taking part during this extremely challenging period. And our network, for accepting the changes so readily. Talking via a screen may not be quite the same as getting together, but it still shows that you are not alone, and that peer support can really help.

## Fertility Education...

Improving knowledge of fertility and reproductive health is essential, and we have been busy talking to young adults and educators about how we can most effectively and inclusively start the conversation with the young people of Wales. By providing appropriate education surrounding all aspects of fertility, we believe that young people will be better informed and able to make educated choices regarding their 'Future Fertility'.

As a significant number of fertility issues are due to menstrual health conditions, we are proud to support Fair Treatment for Women



of Wales (FTWW) and Endometriosis UK, in asking the Welsh Government to make menstrual wellbeing a compulsory component of the new curriculum in Wales. It is vital that girls and young women have access to the information they need to seek medical help at the appropriate time, and possibly improve their chance of conceiving in the future.

Over Fertility Awareness Week, we have raised awareness far and wide. Clinicians, students, patients and FNUK Ambassadors helped us to create films and recordings that educate on both the causes and the consequences of fertility issues, as well as highlighting the emotional impact, and how relationships and work can be affected.

We ran several events during the week. A 'Fertility in the Workplace' session focusing on the mental health impact at work and how to better support employees; a 'Men Matter' event focusing on the male experience; and a 'Friends & Family Brunch & Learn' which is an opportunity for mothers, fathers, sisters, brothers, friends, and colleagues to learn more about what their loved ones are actually going through.

For further information about any of the above, please email:  
[alice@fertilitynetworkuk.org](mailto:alice@fertilitynetworkuk.org)



## News from Northern Ireland

This has been an anxious time for patients here in Northern Ireland with many still affected by the closure of fertility clinics and suspension of elective investigative surgery which is holding up infertility diagnoses.

Thankfully both the NHS and private fertility clinics have been able to re-open for treatments and are working hard to reduce the wait for those who had treatments cancelled or postponed. But anxieties still remain for those worried about increasing age, or impacted by longer waiting times when treatment is time sensitive.

We are reaching more people than ever through our new digital support channels via Zoom, with online Fertility Night-In chats, webinars and our continuing one-to-one support from the team.

Feedback tells us that connecting with others on a similar journey, through our growing private Facebook community, has helped to reduce loneliness and feelings of isolation.

To support the emotional health needs of our contacts, we have been running several wellbeing programmes, with funding from the Tampon Tax Fund and from the Public Health Authority in NI. Our Trying to Conceive groups have accessed a free four-week Yoga programme via Zoom and our More to Life group have enjoyed a free four-week Qi Gong and Wellbeing programme, journaling their journey through the learning. Two CBT programmes will run from October to February next year.



In addition, groups have been able to access the eight-week Mindfulness for Life with teacher Veronica Ellis.

Recognising the importance of supporting the emotional health of patients, all our NI clinics in both the private and NHS sectors, including the new fertility clinic in Belfast In-OVO, have joined the Fertility Network Patient Pledge scheme. This partnership encourages the commitment of fertility clinics to support the emotional wellbeing of their patients.

In the New Year, the NI government at Stormont had pledged to increase NHS IVF treatment to the gold standard of three cycles. This was well supported by all sides when debated in the chamber, just before lockdown in March. It was unfortunate timing that COVID-19 affected the steering group that will take this forward, but I am assured that this is still on the agenda.

It is heartening to hear that the pledge for three IVF cycles has not been forgotten, as Northern Ireland still is one of the worst funded areas for NHS fertility treatments when compared to other areas of the UK. In Scotland, three cycles are funded, although we know that all treatment has ceased to be funded in some areas of England.

Our first day of National Fertility Awareness week focused on #FertilityInequalities, reminding everyone that access to fertility treatment for a diagnosed infertility should be open to all in need. Unless we can make this happen, being able to conceive is still a postcode lottery.

Hilary Knight. Northern Ireland Coordinator  
[hilary@fertilitynetworkuk.org](mailto:hilary@fertilitynetworkuk.org)

## News from Scotland

Now that all the Scottish clinics are back up and running in a COVID-secure manner, the demand for our services continues. We are thankful for the support from NHS clinics in Scotland on our live webinars for patients. These webinars provided a route map on clinics' progress towards resuming their full services, while answering patients' questions.

Sarah and I continue to support patients through this difficult time as the local lockdowns have caused increased anxiety, with patients worried about impacts on their treatment. By keeping them informed of the current guidelines, and offering emotional support if needed, we endeavour to try and alleviate any additional worries during these uncertain times.

We continue with our Zoom patient support services, webinars and closed groups via WhatsApp and Facebook. These are all great platforms where peer support can offer a shared experience in a friendly and supportive manner.

Our online Fertility Yoga series started in April to support patients during lockdown, and has since grown from strength to strength. Although only eight sessions were originally planned, the positive feedback from patients has been overwhelming, therefore we are continuing this right through the winter months.

A key part of our work in Scotland is educating young people on how to protect their future fertility. This has been a huge challenge this year as we would normally

reach out to students during Freshers Week. Last year we visited over 20 colleges and universities across Scotland, engaging with thousands of students. However, this year we adapted to a digital fresher's world with videos, flyers and live events on Facebook. There is still hope that our students may get a belated Freshers Week in the new year. However, until then Sarah and Jenny, our new team member in Scotland, will continue to participate in digital events to ensure we reach as many students as possible to share the importance of protecting their future fertility.

We would like to thank the Scottish Government for their continued support of our services.

Sharon Martin

If you would like to get in touch with the Scottish team, you can find us at:

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[Sarah@fertilitynetworkscotland.org](mailto:Sarah@fertilitynetworkscotland.org)

[Jenny@fertilitynetworkscotland.org](mailto:Jenny@fertilitynetworkscotland.org)



## News from England

While Fertility Network's face-to-face fertility group meetings have not been possible due to the ongoing COVID-19 pandemic, our online groups have been a great source of support to many patients across England. We have 28 regional groups across England; if there isn't one in your area then please join your nearest group. Please do get in touch if there isn't a group in your area as we will endeavour to set one up. Our aim is to have a FNUK fertility group in each county.

In addition to regional groups we also have a growing number of groups that aren't area specific. We have a group for single women who are either going through fertility treatment or considering treatment. We have a group for those experiencing secondary infertility, a group for those experiencing infertility within the Asian community, a same sex couples support group, midwives supporting midwives with infertility, a men's only group and a group for patients pregnant following infertility. Members of these groups can of course join a local group too, but these specific groups can be a great source of information and support when navigating a complex and specialised fertility journey.

We realised there was a need for more support for those who are pregnant after fertility problems and can feel anxious in the early days. We have an online group on Facebook and we also organise monthly online meetings for the group, sometimes with an expert to answer questions. This provides a great opportunity for people to meet one another and get peer-to-peer support.



## Anya

It's been a busy few months as London Co-ordinator. The onset of lockdown generated a lot of media interest about clinic closures and subsequent mental health implications. Amongst others I spoke to BBC London, ITV, and various radio stations to highlight how the new uncertainty was compounding the anxiety already felt by many patients. As always, this is one of the key ways we hope to support people facing fertility issues.

Our Fertility in the Workplace scheme has been very busy, with many webinars delivered to organisations. We talk about the impact of infertility and specifically how workplaces can best support staff facing such issues. Feedback has been hugely positive and we are really pleased to see organisations such as HSBC, LinkedIn and Autotrader really working to better support staff.

I have also been involved with patient perspective for three clinical trials helping again to amplify the patient experience. One of the trials on endometrial scratch was reported at ESHRE and again we hope this will help patients long term.

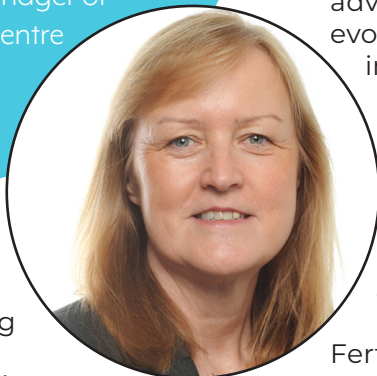
As always do get in touch if we can help in any way.

[anya@fertilitynetworkuk.org](mailto:anya@fertilitynetworkuk.org)



# Working for our patients

By Alison McTavish, Manager of  
Aberdeen Fertility Centre



In 2009, the International Committee for Monitoring Assisted Reproductive Technology (ICMART) and the World Health Organisation (WHO) revised glossary on Assisted Reproductive Technology (ART)<sup>1</sup> terminology stated that “infertility is a disease of the reproductive system by the failure to achieve a clinical pregnancy after 12 or more months of regular unprotected sexual intercourse”.

However, although infertility is a recognised disease, it does not receive NHS funding in the same way other diseases do. The responsibility for health care has been passed from the UK government to the Scottish and Welsh governments and Northern Irish Assembly, which has led to the inequity of fertility services throughout the UK.

Within Scotland, thanks to the lobbying by patients, in the 1990s government ministers recognised that there was an inequity in the way fertility services were being delivered. This led to the Expert Advisory Group on Infertility Services in Scotland (EAGISS) Evidence and Equity 1999 report<sup>2</sup>. This report demonstrated the savings that could be made if patients received timely information and streamlined investigations, which could be used to provide funding for IVF cycles. However, there was no waiting time standard, which resulted in long waiting lists for IVF treatment.

The Scottish Government has played a key role in working with patients and professionals to ensure patients receive gold standard care within an NHS setting.

The National Infertility Group was set up by Scottish Government Ministers in April 2010<sup>3</sup> to bring together service representatives, key national bodies and stakeholder representatives. The group actively provides expert knowledge and advice to the development of existing and evolving Scottish Government policy on infertility and its implementation within NHS Boards. At this time, a waiting time target was also introduced. The 12 month maximum wait was welcomed, as all centres could look to manage staff appropriately in order to meet the demands this would create, and also ensure facilities were updated.

Fertility is still a relatively new specialty and at the cutting edge of scientific development, which can lead to treatment options being introduced with little or no robust scientific testing. The Human Fertilisation and Embryology Authority (HFEA) have very specific information regarding these ‘add-ons’ and state: “For some treatment add-ons, there is not enough evidence to show that they are safe and/or effective at increasing your chances of having a baby.”<sup>4</sup>

The myriad of information and treatment options, available not just throughout the UK but worldwide, make it incredibly challenging for patients to ensure they follow a safe, effective and cost-effective pathway to parenthood.

By having a national agreed pathway through investigations leading to diagnosis and subsequent treatment, the Scottish Government has ensured patient safety and provided cost effective treatment. All treatments provided by NHS funding are in line with the best evidence available.

Although patients can access up to three cycles of IVF, if a person wishing to become pregnant is aged less than 40 years of age, more than one cycle is only provided if there is a good prognosis and at least three eggs collected. Patients who have had a failed fertilisation or who did not develop

viable embryos suitable for transfer will not be offered a further treatment cycle. This is to ensure public money is used to yield the best results for good prognosis patients.

The partnership between the four NHS centres in Scotland has been invaluable over the past six months, as we have met weekly to ensure that patients' diagnostic procedures and treatments could be offered in a safe way throughout the country. This led to a publication, which patients can access on the Scottish Government website: Coronavirus (COVID-19): Fertility Treatment - Plans for Restarting Treatment – Framework.<sup>5</sup>

The Health Minister was aware of the work, and in collaboration with NHS management we were able to re-start treatment safely, with each centre sharing good practice. Working closely with Fertility Network enabled centres to hear patients' views and put information on our websites to ensure we were answering the most common questions being asked – the main one being, "When will I receive my treatment?"

Providing equity eliminates barriers to getting the care needed free-of-charge. Healthcare is a human right and we must strive to provide access to the care needed. With a standard pathway and national criteria in place, GPs and other health care providers can work with centre staff to provide appropriate and safe care for each patient. Having buy-in from the

community setting, through smoking cessation classes and access to dieticians who support patients to meet the national criteria, is helpful for patients, who can undertake this in their local setting.

The agreed care provided is comprehensive and we are in the process of working on national treatment protocols and consent forms which will save time in each centre developing individual documents. Data from each centre is gathered and compared nationally, driving the quality of services. This openness to internal and external scrutiny, can be challenging, however it does ensure patients are receiving high quality care. We are aware that the success of delivering an equitable, effective and fair fertility service is recognised by others and we hope the model we have inspires and mobilises others to achieve this gold standard of care.

Article By: Alison McTavish  
Manager, Aberdeen Fertility Centre

#### References

1. The International Committee for Monitoring Assisted Reproductive Technology (ICMART) and the World Health Organisation (WHO) revised glossary on Assisted Reproductive Technology (ART) [https://www.who.int/reproductivehealth/publications/infertility/art\\_terminology2/en/](https://www.who.int/reproductivehealth/publications/infertility/art_terminology2/en/)
2. Expert Advisory Group on Infertility Services in Scotland (EAGISS)- Evidence and Equity 1999

3. NATIONAL INFERTILITY GROUP REPORT MARCH 2016 First published by The Scottish Government, June 2016 ISBN: 978-1-78652-157-6
4. HFEA Treatment Add on's <https://www.hfea.gov.uk/treatments/treatment-add-ons/>
5. Coronavirus (COVID-19): fertility treatment - plans for restarting treatment – framework [www.gov.scot/publications/covid-19-fertility-treatment-scotland-plans-restarting-treatment-framework/pages/5/](http://www.gov.scot/publications/covid-19-fertility-treatment-scotland-plans-restarting-treatment-framework/pages/5/)



# Fertility treatment add-ons: an update to the HFEA's traffic light system



Going through fertility treatment can be an emotional rollercoaster. There is no shortage of information available online about assisted reproduction treatments, so we know that sometimes it can be difficult to see through the information overload.

As patients often rely on their clinics to guide them towards treatments that could help to increase their chances of having a baby, we've seen more people opting for treatment 'add-ons'. These are optional additional treatments, offered on top of routine IVF treatment, which often come at an additional cost.

Data from our first ever patient survey in 2018 showed that of the patients who had treatment in the last two years, three quarters (74%) had at least one type of treatment add-on.

While the fertility sector has undoubtedly continued to develop since our patient survey, and the COVID-19 pandemic has heavily impacted the way fertility clinics work, patients may be more likely to focus on treatment add-ons again, now that fertility services across the UK have restarted following their closure during the height of the pandemic.

Treatment add-ons have been a key area of focus for us because we don't want patients to spend money on something that will not increase their chances of having a baby. We want to provide patients with high quality information to support their decision-making. This includes publishing more information about the

evidence base for treatment add-ons.

We are keen to encourage innovation and new developments in fertility treatment, but we expect the use of any treatment add-ons in UK clinics to be backed up by good quality scientific research into their effectiveness and safety. We have worked with professional and patient bodies such as the British Fertility Society and Fertility Network UK on an agreed set of principles, such as how add-ons are offered by clinics and what information should be provided to patients.

We also updated our Code of Practice, a 'rule book' for clinics, which requires clinics to tell patients about the success rates of their chosen treatment add-on and the evidence behind this, as well as added costs. Clinics must also refer patients to our website, which lists some of the treatment add-ons offered in the UK that do not have enough evidence of increased chances of a live birth. Our website rates them as part of a 'traffic light' system.

The HFEA's traffic light rated list of add-ons explains what the treatment add-on is, and how the procedures are carried out, but most importantly it includes detailed information about the evidence base for the risks and the benefits (or the lack of evidence) to help patients better understand the effectiveness of these treatments.

A red traffic light is used if there is no evidence to show that the treatment is

safe or effective at increasing live birth rates, and an amber symbol where there is a small or conflicting body of evidence. Green would mean that a treatment has more than one good quality randomised control trial which shows that the procedure is effective at improving live birth rates and is shown to be safe for patients to use. Currently no treatment add-on on our list has a green rating.

Our Scientific and Clinical Advisory Committee (SCAAC) regularly reviews the evidence for treatment add-ons and we recently updated and published new information on our treatment add-ons webpage, including:

- A change in formatting to give each treatment add-on its own separate webpage and further details about each add-on
- How traffic light ratings are decided
- Information about the new process for adding treatments to the traffic-light rated list
- How we work with clinics and professional bodies to continue raising awareness of treatment add-ons issues

While patients can be confident that UK fertility clinics generally provide excellent patient care, the HFEA's traffic-light rated list of optional treatment add-ons is a step towards a more transparent approach in fertility services. We hope it will help to take away some of the pressure many patients feel when they are unsure about IVF treatment add-ons, at a time that is already stressful for many.





## Fertility Network UK Support Line

The emotional response to infertility is complicated, and at times so strong it can seem overwhelming. It is important to tell yourself that the feelings you have when looking into fertility treatment are quite normal.

A medical diagnosis of any fertility issue is for most people a life crisis, which threatens your hopes of achieving a family. Initially, the immediate response may be one of surprise or disbelief, and discovering that you might have a problem can be devastating.

I run the Support Line for Fertility Network UK, having many years of nursing experience and counselling. Perhaps a call to me in complete confidence could provide you with the answer you are looking for, or you may just find it helpful to talk over anything that may be trou-

bling you. Of course you are always best guided by your GP or specialist, but especially during these uncertain times with the COVID-19 virus affecting clinic closures and reopening again, it can help to have someone neutral to listen and talk through investigations, results, treatments and in some cases touching on mental health.

Fertility Network UK plays a huge part in my life, being able to share all my years of experience, in what I hope is a caring and compassionate way. I endeavour to explain anything you need to talk about in the simplest way that we can all understand. It is a privilege to be able to give time to others, when they feel rushed through consultations that they have waited so long for, unable to ask questions. I am humbled by the fact that people keep in touch, so that I can share in their successes, but remembering

some sad times too. This is all part of being the huge family that is Fertility Network UK.

The Support Line is open to all on Mondays, Wednesdays and Fridays from 10.00am until 4.00pm. Call me on 0121 323 5025.

Diane Arnold  
Support Line

*"Hello Diane, thank you so much for your kind words, understanding and advice. I came off the phone feeling hopeful again, so thank you."*

# OUR PATIENT PLEDGE CLINICS

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AGORA Brighton & Hove  
[www.agoraclinic.co.uk](http://www.agoraclinic.co.uk)

APRICITY London  
[www.apricity.life](http://www.apricity.life)

Barts Health Fertility  
[www.bartshealth.nhs.uk/fertility](http://www.bartshealth.nhs.uk/fertility)

Bristol Centre for Reproductive Medicine  
(BCRM)  
[www.fertilitybristol.co.uk](http://www.fertilitybristol.co.uk)

Belfast Fertility  
[www.belfastfertility.co.uk](http://www.belfastfertility.co.uk)

Bourn Hall Fertility Clinic  
[www.bournhall.co.uk](http://www.bournhall.co.uk)

Chelsea and Westminster Hospital Private  
Care  
[www.chelwest.nhs.uk/private-care/fertility-treatment](http://www.chelwest.nhs.uk/private-care/fertility-treatment)

CREATE Fertility  
[www.createfertility.co.uk](http://www.createfertility.co.uk)

Centre for Reproductive & Genetic Health  
(CRGH)  
[www.crgh.co.uk](http://www.crgh.co.uk)

Centre for Reproduction & Gynaecology  
Wales (CRGW)  
[www.crgw.co.uk](http://www.crgw.co.uk)

EmbryoClinic  
[www.embryoclinic.eu](http://www.embryoclinic.eu)

The Evewell London  
[www.evewell.com](http://www.evewell.com)

Gennet City London  
[www.city-fertility.com](http://www.city-fertility.com)

GCRM Fertility Glasgow  
[www.gcrm.co.uk](http://www.gcrm.co.uk)

Hull IVF  
[www.hullivf.org.uk](http://www.hullivf.org.uk)

Jessop Fertility  
[www.jessopfertility.org.uk](http://www.jessopfertility.org.uk)

Leicester Fertility Centre  
[www.leicesterfertilitycentre.org.uk](http://www.leicesterfertilitycentre.org.uk)

London IVF & Genetics Centre  
[www.londonivfandgenetics.co.uk](http://www.londonivfandgenetics.co.uk)

London Women's Clinic  
[www.londonwomensclinic.com](http://www.londonwomensclinic.com)

Newcastle Fertility Centre  
[www.newcastle-hospitals.org.uk/services/fertility-centre](http://www.newcastle-hospitals.org.uk/services/fertility-centre)

NHS Orchard Clinic Craigavon  
[www.southerntrust.hscni.net](http://www.southerntrust.hscni.net)

Regional Fertility Centre (Belfast Health and Social  
Care Trust)  
[www.belfasttrust.hscni.net/services/rfc](http://www.belfasttrust.hscni.net/services/rfc)

Reproductive Health Group Cheshire  
[www.reproductivehealthgroup.co.uk](http://www.reproductivehealthgroup.co.uk)

The Shropshire and Mid Wales Fertility Centre  
[www.shropshireivf.nhs.uk](http://www.shropshireivf.nhs.uk)

Institute of Life MITERA Greece  
[www.mitera.gr/en/department-page/assisted-reproduction-unit](http://www.mitera.gr/en/department-page/assisted-reproduction-unit)

IVF Spain  
[www.ivf-spain.com](http://www.ivf-spain.com)

IVF Turkey  
[www.ivfturkey.com](http://www.ivfturkey.com)



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